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HAMILTON REGION

Mac study looks to help families discuss end-of-life care during COVID-19

By [Maria Iqbal](#) Local Journalism Initiative Reporter

Thu., Feb. 18, 2021 | ⌚ 2 min. read

Long-term-care staff are so swamped with COVID-19 protocols that [end-of-life discussions](#) aren't occurring with residents and families, says a McMaster University professor.

[Sharon Kaasalainen](#), a professor in the school of nursing, says she's hearing from families that they're feeling excluded from decisions about their loved one's care.

"Compassionate care is missing because it's all around public health protocols," she said, noting the absence of these conversations is causing "serious concerns."

Kaasalainen recently met with the [Ontario Long Term Care Association](#) and other long-term-care leaders to raise the issue. The point of [compassionate care](#), she says, is to help people become more comfortable [talking about death](#) and supporting families through that process.

Kaasalainen's research involves helping facilitate conversations about end of life in long-term care. She recently received funding to adapt her research for [COVID-19](#), including by developing [online tools](#) to support those discussions. The goal is to help residents, families and staff prepare for decisions at the end of a patient's life.

While COVID-19 poses [major staffing challenges](#), Kaasalainen says palliative care also has to do with education and a home's priorities.

Her study will pilot online tools at homes in three provinces. Locally, that includes [St. Peter's Residence at Chedoke](#) on the west Mountain, where she expects to roll out the online resources in spring.

The tools in the study include pamphlets on conditions common to long-term-care residents to help both residents and families learn what to expect as a disease progresses.

Pam Holliday participated in an earlier part of Kaasalainen's research. She says the tools taught her to ask care providers more specific questions about the health of her elderly mother, a resident [at Shalom Village](#) in Westdale.

Holliday says palliative care conversations can help even before a person's death. In her case, her mother got sick multiple times, but bounced back.

"You try to make them better, but you try to make them enjoy what they have," Holliday said about the approach.

She adds that the resources are particularly helpful during COVID-19, when there are [restrictions on visits](#) to long-term care.

"We're totally reliant on staff communicating any changes with us," Holliday said. "It's (about) asking the right questions."

Kaasalainen says care conversations can also include the type of music a person would like to hear when they're dying and which loved ones are with them. But avoiding the discussions affects the quality of care during a patient's final days and [how families cope](#) after a death.

“We’re seeing families very distressed, having to make decisions unprepared, and it leads to poor bereavement,” Kaasalainen said. “They have these lingering feelings of guilt and stress.”

In March, Kaasalainen is also planning to launch a national community of practice with the [Canadian Hospice Palliative Care Association](#). It would bring together researchers, care providers and families in long-term care to discuss palliative care.

Her hope is to see families involved in care decisions feeling better prepared.

“The goal really is good death, peaceful death and families feeling guilt-free and prepared for death when it happens.”



Maria Iqbal's reporting is funded by the Canadian government through its Local Journalism Initiative. The funding allows her to report on stories focused on aging issues. Reach her via email: miqbal@thespec.com.

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